

“NOT IN CARE” PROJECT

Background

- Goal: To determine why some PLWH don't get medical care for their HIV
- Impetus for project based on anecdotal reports from service providers that some of the clients they work with are not receiving medical care
- Project sponsored by Seattle EMA HIV/AIDS Planning Council; joint project of the Council's Care and Prevention Planning Committees and the Collaboration Committee
- Planned as adjunct project to the Y2K Care/Prevention Collaboration Needs Assessment

Methods

- Administered interview; each approximately 5 minutes
- Instrument created by work group of Collaboration Committee, with input from members of the Evaluation Committee
- Questions focused on:
 - Main and secondary reasons why participants were not in care
 - What would have to change in order for them to access care
 - Client demographics
- Clients identified and interviews conducted by staff/volunteers at participating agencies (particularly outreach workers)
- 30 agencies enlisted to participate:
 - 11 HIV prevention agencies
 - 9 HIV care service agencies
 - 10 agencies external to the HIV/AIDS Continuum
- Interviews conducted from mid-April through end of June 2000

Demographics

27 total interviews conducted

SEX:

- 23 male
- 3 female
- 1 transgendered (Male-to-female)

RACE/ETHNICITY:

- 17 Caucasian/White
- 6 African-American/Black
- 3 Asian/Pacific Islander
- 2 Latino/Latina

AGE RANGE:

- 9 20-29 years old
- 9 30-39
- 7 40-49
- 2 Unknown

MODE OF TRANSMISSION:

- 12 MSM
- 6 IDU
- 6 MSM/IDU
- 2 Heterosexual (male-to-female)
- 1 Unknown

LENGTH OF TIME KNOWN HIV+:

- 2 Under one year
- 5 1-2 years
- 7 Between 2-5 years
- 9 Over 5 years
- 4 Unknown

Main Reasons for Not Getting Medical Care HIV

- 7 Don't need it
- 4 Lack of trust in doctors
- 3 Have more important things to deal with
- 2 Don't trust HIV medications
- 2 Can't afford it

No respondents stated that they did not know where to access care

Overall Reasons for Not Getting Care

- 15 Lack of trust in doctors
- 13 Don't trust HIV drugs
- 12 Don't want to be judged about drug use
- 11 Don't need it
- 9 Can't afford it
- 9 Worried someone I know will find out
- 8 Have more important things to deal with
- 8 Embarrassed about having HIV
- 5 Nothing they can do to help me
- 5 Dissatisfied with previous care

Several other reasons were mentioned by 3 or fewer respondents

What would have to change for you to get medical care

- 8 I'd have to get sicker
- 6 Change in provider attitudes
- 6 Different drugs or treatment regimens available
- 3 I'd have to get stable housing

Reasons for Not Getting Care by Sub-Population

MSM (n=12)

- 7 Don't need it
- 5 Can't afford it

IDU (n=6)

- 4 Lack of trust in doctors
- 3 Don't want to be judged about drug use
- 3 Don't trust HIV drugs
- 3 Nothing they can do to help me

MSM/IDU (n=6)

- 6 Don't want to be judged about drug use
- 5 Don't trust HIV drugs
- 5 Lack of trust in doctors
- 4 Worried someone I know will find out
- 3 Worried government will know

Reasons for Not Getting Care by Race/Ethnicity

Caucasian/White (n=17)

- 8 Don't want to be judged about drug use
- 8 Don't trust HIV drugs
- 7 Lack of trust in doctors
- 6 Can't afford it
- 5 Have more important things to deal with

People of Color (n=11)

- 8 Lack of trust in doctors
- 7 Don't need it
- 6 Worried someone I know will find out
- 5 Don't trust HIV drugs

WHAT WE LEARNED

- Many agencies told us they could not identify any clients who were not accessing medical care
- Very few participants are not using medical care because they could not access it
- The main reasons people are not using care are because they feel they do not need it, or they do not trust the medical system and/or the treatments available
- Efforts to move PLWH into the care system and maintain participation need to address these issues

WHAT WE DID RIGHT

- Involving both HIV care and prevention agencies
- Reaching out beyond the traditional HIV prevention and care continuum
- Using outreach workers to identify potential participants and conduct interviews
- Developing the instrument as an administered interview instead of self-completed survey
- Keeping the instrument short and straightforward

WHAT WE COULD HAVE DONE DIFFERENTLY

- Involving more people as core oversight group (including Planning Council members)
- Framing the project more fully on its own, rather than as an adjunct to the Care/Prevention Collaboration Project
- Having more lead time
- Spending more time laying the groundwork with individual agencies
- Establishing broader eligibility requirements for potential interviewees at beginning of project, instead of in process

WHAT WE DON'T KNOW WHAT TO DO ABOUT

- Focused efforts were made to solicit input and recruit participants from a wide range of agencies and populations, particularly from agencies whose staff has reported working with clients who are having trouble accessing care
- Responses from many of these agencies was minimal